Chapter 1: RIGHTS AND BASIC PROTECTIONS OF PERSONS WITH AN INTELLECTUAL DISABILITY, AUTISM SPECTRUM DISORDER OR ACQUIRED BRAIN INJURY

EFFECTIVE DATE: November 18, 2022

TABLE OF CONTENTS

| 1.01 | INTROD | UCTION |
|------|--|--|
| 1.02 | DEFINITIONS | |
| | 1.02-1 | Acquired Brain Injury (ABI) |
| | 1.02-2 | Autism Spectrum Disorder (ASD) |
| | 1.02-3 | Behavior Management Plan |
| | 1.02-4 | Coercion |
| | 1.02-5 | Corporal Punishment1 |
| | 1.02-6 | Department |
| | 1.02-7 | Grievance |
| | 1.02-8 | Intellectual Disability (ID)2 |
| | 1.02-9 | Painful2 |
| | 1.02-10 | Person Receiving Services |
| | 1.02-11 | Planning Team |
| | 1.02-12 | Protection and Advocacy Agency |
| | 1.02-13 | Provider2 |
| | 1.02-14 | Restraint2 |
| | 1.02-15 | Review Team |
| | 1.02-16 | Safety Device |
| | 1.02-17 | Seclusion |
| | 1.02-18 | Therapeutic Device or Intervention |
| 1.03 | NOTICE OF RIGHTS AND BASIC PROTECTIONS | |
| | 1.03-1 | Procedure for Notification and Documentation |
| | 1.03-2 | Posting of Rights and Basic Protections |
| 1.04 | RIGHTS AND BASIC PROTECTIONS OF PERSONS WITH AN INTELLECTUAL DISABILITY, AUTISM SPECTRUM DISORDER OR ACQUIRED BRAIN INJURY | |

1.01 INTRODUCTION

This rule sets forth the rights and basic protections of persons with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury in accordance with 22 M.R.S. § 3089 and 34-B M.R.S. § 5605, so that these rights may be exercised and protected. These rights and basic protections may not be restricted or waived by the person's guardian, unless otherwise authorized by law or by a rule adopted by the Department pursuant to 34-B M.R.S. § 5604.

1.02 **DEFINITIONS**

- 1. **Acquired Brain Injury (ABI)**: means an insult to the brain resulting directly or indirectly from trauma, anoxia, vascular lesions, or infection, which:
 - A. Is not of a degenerative or congenital nature;
 - B. Can produce a diminished or altered state of consciousness resulting in impairment of cognitive abilities or physical functioning;
 - C. Can result in the disturbance of behavioral or emotional functioning;
 - D. Can be either temporary or permanent; and
 - E. Can cause partial or total functional disability or psychosocial maladjustment.
- 2. **Autism Spectrum Disorder (ASD)**: means a disorder diagnosed in accordance with diagnostic criteria set forth in the current edition of the Diagnostic and Statistical Manual of Mental Disorders, (American Psychiatric Association), that manifested during the developmental period.
- 3. **Behavior Management Plan**: means a written plan that describes all planned interventions which includes restriction of rights or use of Restraint.
- 4. **Coercion:** means the use of force or threats, including the threat of diminishment of any right or privilege, to cause a person to do something against the person's will.
- 5. **Corporal Punishment**: means the application of painful stimuli to the body, including, but not limited to, hitting, pinching, shocking, and shock devices.
- 6. **Department**: means the Department of Health and Human Services (DHHS).
- 7. **Grievance:** means a complaint by a Person Receiving Services about (1) either an action or inaction by the Department, or a Provider that violates (a) a right or basic protection pursuant to 34-B M.R.S. § 5605, or (b) a Department rule, and that causes the Person Receiving Services harm or may reasonably and foreseeably cause such harm, or (2) the services or supports presently being provided to the Person Receiving Services. Grievance includes a complaint regarding:

- A. The planning process for the grievant;
- B. A violation of other applicable laws;
- C. A violation by a Provider of a requirement of the Provider's license or certification; or
- D. A breach of a contract for services to which the Person Receiving Services is a party or under which the Person Receiving Services is an intended beneficiary.
- 8. **Intellectual Disability (ID)**: means a disorder diagnosed in accordance with diagnostic criteria set forth in the current edition of the Diagnostic and Statistical Manual of Mental Disorders, (American Psychiatric Association), that manifested during the developmental period.
- 9. **Painful**: means that which causes strong emotional or physical discomfort to a person.
- 10. **Person Receiving Services:** means a person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury receiving services from the Department or from an individual, agency, or facility licensed or funded to provide services except those presently in execution of criminal sentences.
- 11. **Planning Team**: means the Person Receiving Services and others identified by the Person Receiving Services and/or their guardian who are responsible for developing a plan for the Person Receiving Services.
- 12. **Protection and Advocacy Agency**: means the Governor-designated agency pursuant to 5 M.R.S. § 19502.
- 13. **Provider**: means an entity, organization or individual providing services to an adult with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury, funded in whole or in part, or licensed or certified by, the Department.
- 14. **Restraint:** means a mechanism or action—whether physical, mechanical or chemical—that limits or controls a person's voluntary movement, deprives a person of the use of all or part of the person's body, or maintains a person in an area against the person's will by another's physical presence or coercion. Restraint does not include a prescribed Therapeutic Device or Intervention or a Safety Device or practice.
- 15. **Review Team**: means a group of persons, composed of a representative from the Department; a representative from Maine's Protection and Advocacy Agency; and a representative from the Maine Developmental Services Oversight and Advisory Board, responsible for reviewing Behavior Management Plans.
- 16. **Safety Device:** means an implement, garment, gate, barrier, lock or locking apparatus, video monitoring or video alarm device, helmet, mask, glove, strap, belt, or protective glove, limited to the person in question whose effect is to reduce or

inhibit the person's movement in any way with the sole purpose of maintaining the safety of the person.

- 17. **Seclusion**: means the solitary involuntary confinement of a person for any period of time in a room or a specific area from which egress is denied by a locking mechanism, barrier or other imposed physical limitation.
- 18. **Therapeutic Device or Intervention:** means an apparatus or activity prescribed by a qualified professional to achieve proper body positioning, balance, or alignment or an action or apparatus that is designed to enhance sensory integration.

1.03 NOTICE OF RIGHTS AND BASIC PROTECTIONS

Each Person Receiving Services, or their guardian if they have been adjudged incompetent, must be provided notice of these rights both in writing and orally, in clear, understandable language and form.

1. Procedure for Notification and Documentation

Persons Receiving Services shall be informed of and must be offered a copy of these rights and basic protections by Providers at the time of intake and initiation of services, or as soon afterwards as is reasonably feasible, and then annually thereafter.

Notification must be made in a form that the Person Receiving Services can easily understand. If the Person Receiving Services does not understand English, is blind or visually impaired, or is Deaf or hard of hearing, the notification must be provided in an accessible format and/or conducted by an interpreter.

2. Posting of Rights and Basic Protections

Copies of these rights and basic protections shall be shared electronically with Persons Receiving Services by Providers, and posted by Providers in a public place where they are clearly visible to Persons Receiving Services. Rights and Basic Protections must be posted in clear, understandable language and in form(s) accessible by the Persons Receiving Services. Additional copies of these rules must be made available upon request.

1.04 RIGHTS AND BASIC PROTECTIONS OF PERSONS WITH AN INTELLECTUAL DISABILITY, AUTISM SPECTRUM DISORDER OR ACQUIRED BRAIN INJURY

All persons with an Intellectual Disability or Autism Spectrum Disorder, are entitled to the following rights and basic protections. Persons with an Acquired Brain Injury are entitled to the rights listed in 1.04-1 to -18. These listed rights and basic protections may be limited or suspended by court order. Providers, entities, organizations, and individuals shall not infringe upon any of these rights and basic protections except as otherwise permitted by law or by the person or their guardian.

1. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the rights enjoyed by citizens of Maine and the United States.

- 3. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to receive appropriate medical and dental treatment and care for physical and mental ailments and for the prevention of any illness or disability, consistent with the accepted standards of medical practice in the community, unless the religion of the person prohibits the treatment.
- 4. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury shall be free from abuse, neglect or exploitation.
- 5. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to vote subject to the rules that apply to all citizens.
- 6. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to religious practice and to refrain from participating in religious activities.
- 7. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has a right to privacy.
- 8. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right, privately, to send and receive mail, phone calls, and internet and other forms of electronic communications without another person interfering, delaying, or monitoring your communication.
- 9. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to unrestricted visitations during reasonable hours unless this right has been restricted pursuant to rules adopted pursuant to 34-B M.R.S. § 5604.
- 10. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to not be discriminated against because of their actual or perceived race, color, gender identity, sex, sexual orientation, physical or mental disability, ancestry, national origin, religion, or age, in employment, housing, access to public accommodations, and the extension of credit.
- 11. All records of a Person Receiving Services must remain confidential unless the Person Receiving Services or their guardian signs a release for their disclosure and except as otherwise provided by law or court order.
- 12. A Person Receiving Services is entitled to access their medical records.
- 13. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury may not be sterilized, except with informed consent and pursuant to court order issued in accordance with 34-B M.R.S. §§ 7001-16.
- 14. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury, who is employed, has the right to engage in employment programs that comply with state and federal wage and hours law and is entitled to fair compensation for employment in compliance with federal labor regulations.
- 15. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to possess and use personal property except when

- temporary custody of clothing or personal effects of a Person Receiving Services by a Provider is necessary to protect the person or others from imminent injury or unless this right has been restricted pursuant to rules adopted pursuant to 34-B M.R.S. § 5604.
- 16. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to nutritious food in adequate quantities and meals may not be withheld for disciplinary reasons.
- 17. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to opportunities for behavioral and leisure time activities, including social interaction within the community as set forth in 34-B M.R.S. § 5610. This right may be waived or restricted only under the rules adopted pursuant to 34-B M.R.S. § 5604 or pursuant to a treatment plan approved pursuant to 34-B M.R.S. § 5603(1).
- 18. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury has the right to physical exercise and recreation, including access to the outdoors and the use of available indoor and outdoor facilities and equipment.
- 19. A person with an Intellectual Disability or Autism Spectrum Disorder may only be subjected to behavior modification or management techniques in accordance with 34-B M.R.S. § 5605(13) and 14-197 C.M.R. ch. 5.
- 20. A person with an Intellectual Disability or Autism Spectrum Disorder has the right to be free from behavioral modifications or behavior management programs that include Corporal Punishment, Seclusion, actions or language intended to humble, dehumanize or degrade, totally enclosed cribs or beds, or Painful stimuli.
- 21. A person with an Intellectual Disability or Autism Spectrum Disorder has the right to be free from Restraint, unless the Restraint is:
 - A. A short-term measure to protect the person from imminent injury to themself or others; or
 - B. Approved in the person's Behavior Management Plan.
- 22. A person with an Intellectual Disability or Autism Spectrum Disorder may not be subjected to a Therapeutic Device or Intervention unless the Therapeutic Device or Intervention is prescribed by a qualified professional, individualized to the person's needs, and designed and applied with concern for principles of good body alignment, circulation, and allowance for change of position.
- 23. A person with an Intellectual Disability or Autism Spectrum Disorder may not be subjected to a Safety Device unless the Safety Device is prescribed by a physician, individualized to the person's needs, and designed and applied with concern for principles of good body alignment, circulation, and allowance for change of position.

1.05 REMEDIES FOR VIOLATIONS OF RIGHTS AND BASIC PROTECTIONS

1. A Person Receiving Services has the right to submit a Grievance against the Department or Providers in accordance with 14-197 C.M.R. ch. 8. They have the right to submit a Grievance to the Department without retaliation prohibited by law.

- A. The Department must provide accessible and regular notice of its Grievance process to Persons Receiving Services, guardians, families, Providers and stakeholders.
- B. Notice of the right to submit a Grievance must be included in informational materials, in personal planning correspondence, and when a Person Receiving Services receives a decision reducing or denying services and supports.
- C. Notice must be written in clear, understandable language and form and include the contact information of Maine's Protection and Advocacy Agency.
- 2. A person with an Intellectual Disability, Autism Spectrum Disorder or Acquired Brain Injury, who receives MaineCare services, has the right to appeal a decision made by the Department in accordance with 10-144 C.M.R. ch. 101, Chapter I, Section 1.
- 3. A Person Receiving Services may submit a complaint to Maine's Protection and Advocacy Agency alleging that a Provider has violated their rights pursuant to 34-B M.R.S. §§ 5606(1), 5611.
- 4. A Person Receiving Services may be able to file a civil action alleging that a person violated their rights pursuant to 34-B M.R.S. § 5606(2).

STATUTORY AUTHORITY: P.L. 2021, ch. 284; 22 M.R.S. § 3089(3); 34-B M.R.S. § 5605.

EFFECTIVE DATE: November 18, 2022